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Biography

Dr. Carter is a 1979 graduate (Magna cum Laude) of David Lipscomb College in Nashville, TN and a 1983 graduate (With Honors) of the University of Tennessee College of Medicine. He is a board-certified Neonatologist who has practiced in academic medicine for 30 years. He is also trained in bioethics and palliative care.

His current practice focuses on providing follow-up care to NICU graduates and serving as a consultant neonatologist in the Fetal Health Center, where he counsels families. He is the local PI for the NIH funded multi-site Environmental impacts on Child Health Outcomes (ECHO) study of a cohort of babies born <30 weeks' gestation. He publishes, lectures, and teaches in biomedical ethics and is the Co-Director of the CMH Certificate Program in Pediatric Bioethics. He is a pioneer in pediatric palliative, having contributed to the field for 20 years, and presently focuses on neonatal-perinatal palliative care. He has authored over 100 peer-reviewed articles and 30 book chapters addressing pediatric and neonatal care, ethics and palliative care, and is a contributing author and editor of Merenstein & Gardner's *Handbook of Neonatal Intensive Care*, the 1st textbook on pediatric palliative care: *Palliative Care for Infants, Children & Adolescents*, and the 1st textbook on neonatal-perinatal palliative care: *Handbook of Perinatal & Neonatal Palliative Care*.

Dr. Carter is a past chairman of the AAP's Section on Hospice & Palliative Medicine and has received honors from the National Hospice & Palliative Care Organization (2003), the William A. Silverman Lecture in Ethics from the Pediatric Academic Societies (2008), and in 2018 he received the William T. and Marjorie Sirridge Endowed Professorship in Medical Humanities & Bioethics at the University of Missouri-Kansas City, School of Medicine. He previously served on the faculty of Vanderbilt University and the Medical College of Georgia after retiring from the US Army as a Lieutenant Colonel in 1996.

Interview Abstract

Dr. Brian Carter begins the interview describing his early career journey exploring the intersectionality of bioethics and neonatology. Dr. Carter viewed some of the early practices of intensivists to "resuscitate people until they die" as exceptionally "egregious," which prompted him to feel 'an obligation. . . to make inroads [to neonatal and pediatric palliative care] via the route of ethics: making better choices, trying to discern [the] right action.'

Dr. Carter then describes the evolution of early practices in neonatology that were visibly distressing to babies, and how the work of him and his peers around children experiencing pain began to change best practices in the field. This scholarly work in the fields of neonatal and pediatric pain helped to create systematic changes to pediatrics, including requiring pain and symptom management for children to be a part of hospital accreditation.

Dr. Carter concludes the interview by describing two of his dreams for the field of pediatric palliative care that would be beneficial to all children, families, and caregivers. The first dream is the ability for families to access hospital-level respite care for chronically and seriously ill children who require advanced medical technologies. The second dream is for increased access to pediatric hospices where children and families could go and be supported at the time of the child's death.

Glossary of Acronyms

<i>Abbreviation</i>	<i>Definition</i>
AAP	American Academy of Pediatrics
AMA	American Medical Association
ECMO	Extracorporeal membrane oxygenation
EPEC	Education for Physicians in End of Life Care
ICU	Intensive Care Unit
IPPC	Initiative for Pediatric Palliative Care
NICU	Neonatal Intensive Care Unit

Interview Roadmap



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[00:00:00]

Bryan Sisk: Today is August 23, 2019. I am Bryan Sisk, I'm in St. Louis, Missouri interviewing Dr. Brian Carter over the telephone for the Pediatric Palliative Care Oral History Project. Dr. Carter is in Prairie Village, Kansas. Thank you, Dr. Carter, for joining me today. To get us started, could you just tell me when your mind turned toward pediatric palliative care as a focus?

Brian Carter: Yeah, it was the late-90s. I have been involved in bioethics since I was a second year resident, when I had the opportunity to take an intensified bioethics course at Georgetown. And I got back the end of that summer—I was at Fitzsimons Army Medical Center, which is now closed, but the campus is where the University of Colorado Health Science Center campus currently exists. I was asked to start an ethics committee, this was in 1985. So I did with others and have maintained interest in that—sort of working my way from the ground up doing ethics consultation in adults as well as pediatric cases, and became familiar with the program that Mildred Solomon, who is currently the President of the Hastings Center, was running just outside of Boston.

She had a grant and it was supported by some private foundations, and it was basically to look at decisions near the end of life. The way in which this was done was to work via hospital ethics committees to educate them and to help them to become more facile in addressing end of life issues as they contended with ethics consultations.

As some have been known to say, ethics has cut its teeth on beginning of life and end of life cases. So, she and her colleagues were administering this program over a number of years. I participated in that and had local people trained. And then, also it was a train the trainer kind of situation. I also trained others while I was in the military.

When I got out of the military in 1996, I went to the Medical College of Georgia, on the faculty there. I was a neonatologist. I became intrigued with end of life matters as they existed in the practice of neonatology, which I had always paid attention to, but never knew how to ground in particular field or domain, other than ethics.

So, while I was there at the Medical College of Georgia, myself and a couple of others put together a four-year longitudinal ethics curriculum for the medical school. And I had done some work on informed consent and the NICU [Neonatal intensive care unit] with a nursing colleague, and went to a meeting of the American Society of Law, Medicine, and Ethics, I think it was in Boston in 1997 where I met Anita Catlin, who is a nursing doctor, a doctor of nursing science and a family nurse practitioner, who had just completed a project in which she looked at resuscitation as was

taught through the Neonatal Resuscitation Program by the AAP [American Academy of Pediatrics] and the American Heart Association. She, as well as myself, had made the observation that there was no exit from the loop of resuscitation. And so she had used a small grant from the AAP to interview clinicians and basically was told, "This is what we do. We resuscitate people until they die because we don't know when stop. There's no instruction on when to stop, and we don't know that it's right to stop, we just keep doing it." And so she reported that, published a paper, and she was there at the conference and she and I struck up conversation about how interesting it was that that's what intensivists do, is they just keep doing, they don't know when to stop. I've had experiences with colleagues in which that was absolutely the case to the point that a child would die on ECMO [Extracorporeal membrane oxygenation], because nobody would stop. I felt that was rather egregious and had tried to make inroads via the route of ethics: making better choices, trying to discern right action and can do that.

And so it was this interesting convergence at the end of the '90s. About that time, I think was '98, the AMA [American Medical Association] held it's first EPEC [Education for Physicians in End of Life Care] course in Chicago and said that they would train the trainers, so I went to become trained. At that time, EPEC stood for Education for Physicians in End of Life Care. The program was directed at adults, but at the meeting there were a few of us that were pediatricians, including Dr. Marcia Levetown and myself. We struck up a friendship, and the decision was made to try to work to improve palliative care for children, because as she and I both in different settings had told people, well kids die too.

In fact, as a neonatologist, you are never too far from death. If you look at survival from the NICU, it's wonderful in a grand sense, but if you look at infant mortality in this country, about a half of the children, half to two-thirds of children that die before their first birthday, die because of issues related to the perinatal period, whether it's prematurity or birth defects or sepsis or SIDS or any number of things.

So, I felt this obligation of trying to make improvement. I had these two wonderful colleagues and that was pretty much the birth of my interest in pediatric palliative care. It sort of came with the convergence of ethics and a clinical need, as I saw it, in neonatology and then more broadly in pediatrics.

[00:07:45]

Bryan Sisk:

So, one thing I find interesting is the strong interest in ethics and palliative care. Have you found over the years that that's been a tension between the goals and attention of ethics versus palliative care? Have you found that they've aligned very well for you?

Brian Carter: I think they've aligned rather well. I think, if I could put it in a simple illustration, it would be that ethicists, be it clinician ethicists or a PhD, philosopher ethicists, you've basically paved the way for palliative care in this country. In other words, from notable cases such as Karen Ann Quinlan and forward, it was the ethicists that basically cleared the path and said, "It would be okay to stop. It would be okay not to be on life-sustaining medical treatments. It would be okay to remove a feeding ventilator or dialysis, any number of things." And yet, the ethicists in and of themselves were not the caregivers. So, they cleared the path and said, "It's okay." Now we need clinicians that will accept that it's okay and manage patients who are making decisions to avoid or to withdraw life-sustaining medical treatments.

Originally there was this end of life focus that I think the ethicists gave validity to, and the clinicians, be they oncologists or intensivists or general medicine or pediatric docs, ultimately stepped up to was, "Yes I can do this. I can limit what we are doing. I can palliate. I think that's the right thing to do." And then maybe if those clinicians were inclined towards understanding bioethics more themselves, I don't know that actually or have not seen empirical data to that effect, but I do know personally of a number of people that that was the case. I think that ethics paved the way for palliative medicine in this country, and they have generally worked in tandem very well.

[00:10:19]

Bryan Sisk: As you were starting out, late 90s after you went through the EPEC course, you talked about Marcia Levetown, who is obviously in Texas, and the Anita Catlin. Other than that, were there a lot of other people of similar mind that you were interacting with?

Brian Carter: I can't say that there were a lot of other people, but there were other people that I would say a number of clinicians from varied specialties that would realize that we perhaps could do better by patients and their families instead treating them excessively to the point that well-intended treatments no longer hold merit, treatments that are just persistent interventions, and would be willing to redirect care towards palliation, comfort, and improved quality of life.

So, I think all of these things were sort of happening in a general sense. I know that I was fortunate to meet a number of people both through ethics circles and ultimately through palliative care circles as the specialty grew.

I had the good fortune to meet with some hospice physicians, one who I worked with while I was at Vanderbilt, John Mulder, M-U-L-D-E-R, a family physician who was boarded by the American Academy of Hospice Palliative Medicine, became a hospice physician. He was a key person that I partnered with when I was at Vanderbilt. The other colleagues there

included Jim Whitlock, who is a pediatric oncologist, and Mary Jo Gilmer, who is a clinical nurse specialist and is on the faculty of a nursing school at Vanderbilt. The four of us sort of partnered and one of the reasons was my past work with Milly Solomon's group and decisions made at the end of life and the recognition that there was a need for a better study and clinical practice.

Pediatric palliative care became involved in a program called the Initiative for Pediatric Palliative Care or IPPC. The groundwork for that was done in the late '90s. I actually participated in some of that groundwork while I was with the Medical College of Georgia and when I relocated to Vanderbilt in 1999 carried that forward. And Dr. Solomon and colleagues received funding for a five-year project to develop and implement improved palliative care for children.

So, the initiative for pediatric palliative care ran until about 2003, 2004. I participated in training and also trained others and met many people through those activities.

[00:14:04]

Bryan Sisk:

So, you had done the research with Solomon. Did you feel like you had mentors in how to provide the clinical care, or did you feel you were learning it along with others as you developed?

Brian Carter:

[laughs] No, it wasn't the terribly well-mentored work. In neonatal medicine, I had no qualms, no problem of taking care of babies and young infants. But it's just an asset because I had done some work with Dr. Solomon's group, although I wasn't one of the principal investigators with her group. Dr. Catlin and I did a study basically to derive what might be best practice in comfort in palliative care for newborns and young infants. That was published, I think, in 2002.¹ I did a study at Vanderbilt looking at how the end of life for hospitalized children actually mapped out and that was published in *Pediatrics* in 2004.²

But looking to mentors for clinical practice, communication skills, ethics, no, there really weren't any that I could turn to and say they were great mentors. I had some good support from previous mentors in neonatal medicine including the late Jerry Merinstein who was both a mentor of mine in residency and in fellowship, and the late William A. Silverman who I had wonderful email conversations and phone conversations with. I only had lunch with him once, I think, because the only time we met years ago at the Western Society for Pediatric Research meeting in Carmel. He

¹ Catlin, A., Carter, B. (2002). Creation of a Neonatal End of Life Palliative Care Protocol. *Journal of Perinatology*, 22(3), 184.

² Carter, B., Howenstein, M., Gilmer, MJ., Throop, P., France, D., Whitlock, J. (2004). Circumstances surrounding the deaths of hospitalized children: opportunities for pediatric palliative care. *Pediatrics*, 114(3), 361-366.

used to sign off on his emails, "Strength to your arms!" with an exclamation point.

I only later learned Bill, himself, died of chronic renal failure and he elected to cease dialysis. But his wife was a hospice nurse, and she'd just started in the last couple of years and Bill had been married to her for a number of years before he passed. I think being an avid neonatologist, investigator, publisher, he became quite a critic of how people practiced neonatology without evidence. So, I found it interesting later when I learned that his wife was a hospice nurse, and I thought, so he basically allowed for this to be part of his life and his wife's clinical practice, and subsequently she was even a volunteer after he passed. She was a hospice volunteer in the San Francisco area. But evidence was something that he would remind we needed to garner. So get out there and do some studies and produce some evidence that this is good for kids and good for families.

But I cannot tell you that I had a mentor at my side who would say, "This is how you do this, Brian." It was a lot of trial by fire, and persistence. You just put your head down and keep going forward.

[00:18:10]

Bryan Sisk:

So, when you were developing this interest transitioning from ethics to what became pediatric palliative care, what were the biggest challenges you were observing in the care of these infants that were suffering and dying?

Brian Carter:

Well, as is true in ethics consultation, I think anywhere it's been studied, communication was the principle area for development. Communication being not just having the care conferences and making difficult decisions with and for families and their kids. But even communication within one's own mind, talking to yourself about is this right? If this is right, how, why do I believe this? What foundation of knowledge supports this? What philosophic or theological frame might say that this is okay? How do I talk to professional colleagues, those that might consult me or those with whom I'm working every day? How do I communicate electronically and the record, telephonically on the phone, by hand if I'm still writing things? I mean, what word choice really is best, and how do you select the right words.

I think it's Ira Byock the quote may be attributed to, but I've always held it in high esteem, and that is, "The good palliative care physician wields words like a surgeon wields a scalpel." And I heard that a number of years ago and I've never forgotten it. And I think it's very present for me as I try to speak to others, whether it's in a general formal educational venue or a conversation like we are having or perhaps an informal consultation or teaching trainees. Words matter, and the right word at the right time

delivered in the right manner with the presence of mind, but also of body and of soul to be present and then listen, be sensitive to how that word is received and responded to. I think that is probably the biggest challenge that I've realized. I mean symptom management was sometimes challenging but most of the time not. Decision-making was sometimes challenging, but I was fortunate that I had been trained in ethics and I felt fairly facile about helping people with decision-making.

But communication, I think, was the biggest barrier, and I think I still observe that today. Some people are not inclined to go there. They don't want to have those kinds of conversations. They don't like to use those words or to think about those words in that manner. And they would rather let somebody else do it.

I once worked with a colleague in neonatology. He says, "You know, I don't like to talk to parents, I'll let the social worker do that." I about fell off my chair. "What?" I mean these things happen. And I thought, "Well, at least he's being honest. He's an intensivist. He was an investigator. He's a thoughtful man in a certain light, but he doesn't really want to think about those other things." I think intensivists are inclined to do, and do, and do, and do, and not necessarily to pause and to think. So, I think, communication has been probably the biggest, and may remain, the biggest obstacle.

[00:22:58]

Bryan Sisk:

Another thing I came across in my research was the work of Sunny Anand especially in pain in neonatology. So, prior to his work, it seems like there was a lot of question in the field, prior to the mid to late-80s, of whether infants were able to experience pain and there's a lot of procedures they went through that later on found out was probably very painful. How did you observe, or did you observe a transition in the way that neonatologists viewed pain eventually?

Brian Carter:

Oh yeah. Sunny's paper was published in '82 or '83 and I graduated med school in '83 and started my pediatric residency at Fitzsimmons. You know we did circumcisions without any pain medication or no lidocaine blocks, what have you, and it was ridiculous to think that the infant didn't feel pain. Nobody had really felt comfortable with administering systemic analgesics or sedatives to a baby boy just for a circumcision. So we would put a little sugar on the cheesecloth or a gauze pad, some sugar water, and let him suck on that. Which had, historically that's been used for centuries on what's been commonly referred to as a "sugar teat" in many societies that practiced ritual circumcision. Something as simple as that you could tell, "yeah, this hurts the guy." In fact, I developed a practice which say, "well, you have to hug them if you're going to hurt them." So, after I was done, I'd pick them up and swaddle and held them. With a pacifier in their mouth, they would sooner or later get quiet. But it was obvious that we

were doing something that hurt the baby, and the baby had normal innervation and responsiveness to pain stimuli.

But it took a while. By the end of the decade of the 80s, we learned how to do dorsal penile nerve blocks, and that was great to do a circumcision with. The baby never uttered a peep. People would look at you and say, "When you going to start?" "Oh, I'm done."

Sunny's work, in particular, that dealt with the use of fentanyl in thoracotomies for cardiac surgery and otherwise,³ I think was foundational and really launched subsequent decades of research that continue to this day, about the developing nervous system and nociception and responsiveness and how we can discern that even in the young fetus in utero. Certainly, the fetus, now newborn at 24 to 26 weeks, we can certainly see that.

Other procedures, as you know, that has been commonly done in the neonatal ICU [intensive care unit], anything from intubations to spinal taps or placing IVs or doing arterial lines are, in fact, painful. And so, we have, in this day and era, developed protocols really.

I want to say they are common to the point that they are everywhere, but I know better. Because when it's studied in any country, and it has been studied in Europe as well as North America and South America, pain management for the newborn is extremely variable. So, the simple nurse's rule that if you think it would hurt you, if someone were to do this procedure to you, then you should think that it's going to hurt the baby, ergo you should treat the baby.

To a more complicated understanding of what actually constitutes a nervous system and how it works in a 24 or 34 or 44-week gestation newborn, and how does recurrent pain and perhaps tissue injury from repeated painful stimuli, such as heel lancing, change the developing brain and responsiveness of the baby to pain at subsequent points in time.

So Ruth Grunau has done excellent work years ago⁴ that demonstrated that if a child, a boy, had circumcision but without analgesia the nature and the duration of his cry, while having his immunization at 2, 4 and 6 months, was different than a boy who did have analgesia for his circumcision. So that there are lingering effects on behavior and that's sort of a surface, it's gone much deeper since then.

³ Anand, KS., Sippell, W., Aynsley-Green, A. (1987). Randomized Trial of Fentanyl anaesthesia in Preterm Babies Undergoing Surgert: Effects on the Stress Response. *The Lancet*, 329(8524), 62-66.

⁴ Grunau, R., Craig, K. (1987). Pain expression in neonates: facial action and cry. *Pain*, 28(3), 395-410.

So, I think, paying attention to painful procedures certainly has been the norm. But I can't say so, and we still do a lot of things that are painful to babies, but we try to mitigate that pain with topical anesthesia or reduce the frequency of such things or use non-invasive monitoring.

Certainly, the end of the 1990s into the early 2000s, when the drug commission for accreditation of hospitals and related organizations, taught us that we should treat pain better or perhaps make pain the fifth vital sign, we saw a ramping up of analgesics that have been used even for sedation for babies on assisted ventilation. That might have the deleterious thing as we looked out at the opioid crises. So, we weren't doing real pain up until the 80s and then we went overboard in the early 2000s and now we are sort of back pedaling and trying to find the sweet spot.

But that's, as you know, only one symptom that a baby may have. Babies have restlessness. Babies have itching. Babies have neuro-irritability, seizures and nausea and vomiting and diarrhea, just like big kids do who are receiving palliative care. So symptom management is important. Then we are broadening our understanding of pain now, chronic pain and using different medications including gabapentin, sometimes ketamine, certainly clonidine and, I think, doing a better job than we did 20 years ago.

[00:30:42]

Bryan Sisk:

So, in your practice, do you do palliative care specifically within neonatology or you do broader palliative care as well? What is your clinical background?

Brian Carter:

[laughs] I, of course, was an advocate—somebody called me a pioneer, I don't know if I like that term—but an advocate for pediatric palliative care in general, and perinatal palliative care, more specifically, just to get it on the map. In other words, I found that it needed champions. You know that really was behind Marcia and I co-editing the first book on pediatric palliative care in 2004.⁵

We were at an American Society for Bioethics and Humanities conference. I had been on a panel and had been talking about palliative care and a publisher approached me and said, "Will you write a book?" I said, "What? I don't know, I guess I could write a book. If you want to write a book on palliative care, then Marcia Levetown should write it." They said "Well, we'd like for you to do it with her." I said, "Well, have you talked to her?" "No, will you?" So, that all came together pretty quickly, then it takes a while to produce a book.

That was important in advancing the field although I have never practiced general pediatric palliative care other than as an intensivist. The last two

⁵ Carter, B., Levetown, M. (2004). *Palliative Care for Infants, Children, and Adolescents: A Practical Handbook* (Foley, K., Ed). Johns Hopkins University Press.

years I was in the army, I was at Walter Reed in Washington, D.C., and not only did attending blocks in the neonatal ICU but also in the pediatric ICU. And so, I walked in one day and there was a 17-year-old who that just hemorrhaged into his brainstem, glioma, and was nearing the end of life. There was a six-year-old in status asthmaticus who was intubated, and here was a 4-year-old who was a recipient of child maltreatment and had bleeding ulcers because of being punched. I was thinking, "I'm so glad I'm a neonatologist. I could not handle this day in and day out." And symptom management and being an intensivist was sort of the call of day—do, do, do, fix, fix, fix and sort of help, but I have no and have never claimed to have expertise to be a palliative physician for older kids or adults.

I think my broadest practice when I was at Vanderbilt, I would treat kids up until a year or two of age, and they were all kids that didn't have cancer because if they had cancer, then Jim Whitlock take care of them. If they were older than two, then John Mulder would take care of them if they didn't have cancer. So, you sort of split the workload until the service eventually evolved to where the hospital hired a palliative boarded doctor. So, I've never practiced pediatric palliative care with big kids.

Currently, my practice is rather limited, it's all perinatal. I'm occasionally consulted in the neonatal ICU around pain issues or palliative issues, but I chose not to become boarded in pediatric palliative care when the boards were being established. I said, "You know I'm a neonatologist. I'm a happy neonatologist. I've been taking care of babies for 25 years and I know how to take care of babies around the end of life, and I'll be happy to teach other people, but I don't need to get boarded in palliative medicine and pretend to do things that I'm not going to do. I'm just going to continue as a neonatologist." So, I chose not to pursue boards and, in that manner, became sort of the generalist palliative care doc in the NICU, not the specialist palliative doc.

But I think what needs to happen in palliative medicine is exactly what happened in ethics. Pediatric ethics is a niche group within bioethics generally, but bioethics generally grew up over 30 years from Quinlan in '76 to Cruzan in '91, to Schiavo in 2005.

What happened was the language of bioethics became normative. People learned, and it's not the only way to analyze ethical cases, but people learned how to use the principles, the four standard principles in beneficence, non-maleficence, justice, and autonomy to at least approach, in some manner, an analysis of an ethical case. And what happened was during that same time, yeah, there were more people trained in ethics. They sometimes had master's and sometimes had PhDs and oftentimes had MDs and RNs. What happened is that now the language of ethics is normative in the healthcare arena. That doesn't mean people don't need

help, but it was just lines and competency across the board. There is an expectancy every one of the specialty boards of American Board of Medical Specialties that you have some foundational ethics knowledge how ethics pertain to your practice. And that's taught—in every medical school in the country teaches ethics. That wasn't the case 30 years ago, but that certainly is now.

I think what needs to happen with regards to palliative care is very similar. Everybody needs to learn common precepts of palliative care: the language, the communication, the decisional skills, when to get a specialty consultant, when you need help with symptom management, how to help transitions from inpatient to outpatient to hospice, how to engage volunteers, how to do the collaborative work across disciplines, the interdisciplinary collaborative work that really constitutes good palliative care.

So, I think that's been growing and will continue to be a growing phenomenon knowledge base in generalist practice. I don't think it'll take 30 years. But pediatric palliative care, *per se*, has not been around for about 20 years.

I do think that some of us make decisions about where we think our role is, and I've chosen to continue my path as an educator, instigator, advocate, author, speaker, and help with program development and design. But, no, I don't practice pediatric palliative care for big kids. I trust my colleagues that do and I admire them.

[00:38:46]

Bryan Sisk:

So, as you were starting this kind of mid-career refocusing to triangulate palliative care and ethics and neonatology, what were some of the big challenges you ran into?

Brian Carter:

At times, as an academic physician, you're always wrestling with the calendar. I think in private practice you've got pretty much control of your calendar within your group. People know what you are supposed to do. You show up for work, and you take your call, and you have your time off. In academia, you've got this constant challenge to produce, to do scholarly work, to mentor, to publish, to advance the field or start a new service line. What I found to be the most difficult was actually getting credible time acknowledgment from hospital leadership, acknowledgment from colleagues in neonatology as well as throughout the department of pediatrics that what I was doing to advance the field of pediatric palliative care was actually worthwhile and not chasing off into left field, ignoring what was really supposed to be going on. So, I think time and the respect of the burgeoning field of pediatric palliative medicine.

[00:40:22]

Bryan Sisk: When did you start to see that respect or appreciation of that field change, or have you?

Brian Carter: Well, it's in flux. I've probably been in half of the pediatric hospitals in this country, and it is the constant challenge for local champions to gain a foothold and gain respect and the allowed resources and time to develop what they know is necessary and good and will reap reward for families, patients, and caregivers, which are the three stakeholders in palliative care.

Families because they are in a crisis and they need help and they want the best for their child, even if that child is going to die. Kids because they need to be able to do the things kids do, to play and to learn and to develop. Albeit with critical illness, chronic illness or debilitating and degenerative processes, we owe it to our kids to help them live as normal a life as possible. I think that's what great societies do is take care of their future generations. Then caregivers, as you know, caregivers are adversely affected by caring for children whose symptoms are managed well, whose families are in crisis and not supported, whose clinicians are doing things to instead of for the child and basically stirring the pot and developing situations of moral distress.

So I think all three parties stand to benefit by leadership, be it department chair or hospital CEO or chief of staff or chief of nursing, or a division chief in oncology, cardiology, critical care or neonatology, acknowledging that, yeah, this is a vital part of taking care of kids who may not ever go home and that we owe it to them and to all of those parties I previously named to give them resources to do the best job possible.

That really gets back to the late-90s phenomena that even brought me to this reality when I was meeting up with Anita Catlin and Marcia Levetown. It was like "Wow. You know, we're in academic medicine, we are supposed to be developing best practice based on evidence and scholarly work. And if we can't do that, then we need to figure out why."

In neonatology, we have just made the great advance of surfactant in the decade of the '90s and saw it literally save of millions of kids' lives and improve the quality of life for others.

So, we were doing all these wonderful things to treat diseases but when it came to dying, there was no consistency in the care of the dying child. It depended on who your attending was, or who your nurse was, or who your social worker was, and did they have the skillset, were they inclined to bring it to bear, could they communicate, did they get along with families—all of those things. And I looked at my colleagues and I said, "We're in academic medicine. We are supposed to be developing and perpetuating good practice, best practice. If we're not, and instead it's just

"you get the kind of care that whoever you get luck of the draw on weekend or week night or week day to be your caregiver," then we're perpetuating error for our trainees because they are basically seeing what's going on and they are not stupid about it." They would say, "Well wait a minute. How come nobody's doing better by this?" So, to me it was a demand of academic medicine that we develop better practices in caring for children with chronic, debilitating, and critical conditions.

So, I carry that forward to today when you asked the question, what's the biggest challenge now or have people overcome this issue of merit worthwhile sense of palliative care and giving it the resources, it needs.

Now you could ask me about half a dozen hospitals and there are be at least three different answers. Because you can go to one center that has a palliative care fellowship. Yeah, they've got two or three faculty and they have some good nurses and a chaplain. Maybe they have a child life person or psychologist, maybe not. They don't really have much of a research arm, but they are providing palliative care and they are training young trainees to do it.

Then you can go to some place like Akron, Sarah Friebert's shop or to Children's Hospital of Philadelphia, and you've got these stellar exemplars at Boston Children's with Joanne Wolfe, who are doing robust research, every facet of care you can imagine with the full complement of an interdisciplinary team. It's that way across the country.

When you look at, Joanne Wolfe actually said this 10 years ago, when you've seen one pediatric palliative team, you've seen one. There is no standardization. So, this is constant challenge. It was a challenge that I ultimately became frustrated with, that drove me back to my original love of bioethics and had me come to Kansas City to work in the Bioethics Center with John Lantos and as well as to work in neonatology and be an advocate for pediatric palliative care, but I did not come to Children's Mercy in Kansas City to be a palliative care doc.

So, everybody is making strides forward. Most of the time they are small baby steps. Every now and then, there's an impassionate story of a child and a family, and there might be a large philanthropic gift that endows programs, but those are the exceptions, they are not the norm. It's a struggle for resources and respect and time.

[00:47:25]

Bryan Sisk:

Thinking back more globally, in retrospect, what do you think was the spark that really drove the initial development of this whole field of pediatric palliative care?

Brian Carter: I think it probably has to do with the fact that medicine was making such great strides in the decades of the 70s, 80s, and 90s with improved outcomes for many, many conditions, and still having to reckon with the fact that there are conditions that children have that bring them to hospital and we'll never see them go home. Still having to reckon with the fact that children die, and our society is fairly death averse and historically it's been out of sync with nature for children to die before their parents. So, it's driven, I think, globally a desire to mitigate that. I don't think it's ever going obliterated. But I think it has to do with the desire to help kids be kids and to passionately and compassionately take care of families who are wrestling with circumstances when that's very hard.

[00:48:57]

Bryan Sisk: How much do you think the adult hospice movement affected the development of pediatric palliative care?

Brian Carter: It absolutely affected it because again, it made it normative to consider palliative care in hospice. Now, as you are aware, pediatric palliative care is not rolled out in the same manner that adult palliative and hospice care is. It's far more of a supportive care role in pediatrics but might be of a other greater duration than is typically the case with adults. But were there not to have been a Dame Cicely Saunders, you know, decades ago or the movement that was started here in North America a few decades back, even Elizabeth Kübler Ross' work *On Death and Dying*, started to, needed to lay the groundwork for there to be a place, a role for palliative and hospice care. Had it not been present in the adult world, it would have been far more difficult for it to be envisioned in the pediatric world.

[00:50:17]

Bryan Sisk: Have there been any negative influences of the adult world on the pediatric world in palliative care?

Brian Carter: Well, there is always the simple, or the simpleton's model of "children are just small adults," which we know is not true. Being in the army, I once said that adults are just big babies. *[laughs]* But it's not necessarily true the other way around. Baby physiology, child physiology, the whole developmental realm of childhood and its breadth of everybody's system, but most importantly psychosocial development, makes children so unique and pharmacologically so, they handle medications differently.

So, I think there have been mistakes along the way where people just tried their best to take care of kids but thought of them as just little adults and adjustments need to be made. The holistic approach of taking care of a child I think is a little bit different than that of taking care of an adult.

[00:51:39]

Bryan Sisk: As you look over your career, what do you think have been the biggest changes in the care we provide to the children that are dying and suffering from serious illnesses?

Brian Carter: The biggest changes are in my mind; an intention and a desire to, albeit, but they may have these chronic and debilitating illnesses, that they are given voice and value and respect and that extends to their families. I think, in one sense that's sort of an idyllic goal of pediatric medicine anyway. But when your child is dying or in a life-threatening situation and people didn't know what to do, or how any facet of palliative care might be beneficial, then I think we are sort of stuck. And I think the fact that pediatric palliative care exists is a great thing. It brings respect to the full circle of life. It doesn't necessarily avoid or absolutely mitigate the tragedy of child death when that occurs, but I think it brings respect and value and voice to that.

[00:53:22]

Bryan Sisk: As you look back on all of the different contributions you've made for this field, what's your favorite contribution you've made?

Brian Carter: I think it's all been conversations. They could be small conversations or public conversations, or conversations carried out in the literature or books. I feel fortunate to have been able to have a hand in a couple of books. The one with John Hopkins University Press in 2004⁵ and second edition in 2011,⁶ and have a book coming out this fall with Springer on perinatal and neonatal palliative care that co-edited with two nurses.⁷ In so many ways those are just conversations carried forward and/or they engender new conversations. So, that's it. It's just love kids and love to help them.

[00:54:26]

Bryan Sisk: Looking globally at the field of pediatric palliative care, what do you think is the strongest aspects of the field right now? What are the brightest lights going forward?

Brian Carter: The brightest lights are those shown on research and scholarly works produced by faculty, produced by trainees during their fellowships, produced by interdisciplinary teams looking at models of care and practice. And I think also helping people to understand that this is a valid field that has a permanent place in the repertoire of pediatric medicine and ultimately, if that can be encoded in some manner with public policy and funding, I think that would be the brightest spot. You know the concurrent care initiative was a very bright spot. And I think if we can keep that type of focus, it will continue to be a bright future.

[00:55:48]

Bryan Sisk: What do you think are the biggest challenges? Where does the field mostly needs to grow?

⁶ Carter, B., Levetown, M., Friedbert, S. (Eds.). (2011). *Palliative Care for Infants, Children, and Adolescents: A Practical Handbook* (2nd ed.). American Academy of Hospice and Palliative Medicine

⁷ Limbo, R., Wool, C., Carter, B. (Eds.). (2019). *Handbook of Perinatal and Neonatal Palliative Care A Guide for Nurses, Physicians, and Other Health Professionals*. Springer Publishing Company.

Brian Carter: Well, from the standpoint of continued struggles of creditability and respect, garnering good knowledge from the research, whether that's on symptom management or models of care or even good qualitative studies that are correctly done and shared, as well as recognizing that what's right for one isn't right for all. And so that changes with age and diagnosis, but it also changes with culture and ethnicity and religious frame. When you go across the ocean it's different. I visited the Far East and South Africa and South America. Every place is little bit different. Everybody's learning and making strides forward but at a different pace and with a different priority. So, not trying to unify it as this is the right way and here's the prescribed steps to take, but knowing that we can grow together, even at different rates. I think that's a challenge but also will bring promise.

[00:57:19]

Bryan Sisk: Wonderful. I've got one last question. And for this question, I'd love for you to dream out loud. If budget and politics and all the things we've talked about, if none of those were obstacles, what would you ideally want care for these children suffering from illnesses to look like in another 10 years?

Brian Carter: I would wish for easily two or three things and they've been on my dream list for the last 10 or 15 years. I would wish that there would be a unit in every pediatric hospital that had a bed space that might be one, two, or four or maybe even six beds, to provide respite care for kids that was funded, so that kids that were on life support or chronically debilitated at home can come to the hospital and be cared for in a loving environment and their parents be given respite for a period of time, whether it's a three-day weekend or a week or longer. Because it's terribly burdensome and difficult to manage children on technology at home and run into circumstances where we realize that the end of life is foreseeable. So, respite care would be one.

Another would be similar to that in one sense would be pediatric hospice houses that exist in the U.K. [United Kingdom] We've got maybe three in the U.S. [United States] *[laughs]* There's probably 23 in the U.K. But a place where kids and their families can go and live together and be together and if the time is appropriate and the desire is there, be together even at the child's time of death. And if that's not possible, then having the right support for kids at home all across the country or around the world so that they are not alone and they are not in pain when they die.

That should probably be, the most readily come to mind, persistent dreams I've had for kids. I've been in a couple of hospice houses and they are phenomenal and you wonder why every city that has a children's hospital doesn't have one. But every city that has a children's hospital doesn't have a functional palliative care team, so maybe that's the top of the list.

[01:00:17]

Bryan Sisk: This has been wonderful. Those are all the questions that I have. But is there any part of this history you think I've glossed over, or I really should dig into in the future?

Brian Carter: No, I appreciate the work you are doing. I think it's important to understand movements in medicine. I think medicine and all of its specialties has gone through different cycles, or perhaps repeated the same cycle in those attempts to cure. And then once we've maximized curing, attending to the quality of life of survivors. And then now as we've moved beyond that with many chronic diseases, quality of life then leads to quality of life of survivors whose life is getting shorter, and so the role for palliation. But I think you could pretty much pick any specialty in medicine and it's been about cure and then when it's sort of plateaued, we try to improve quality. I think palliative care is on that spectrum. It's part of the quality spectrum.

[End of Audio]
